Chapter One
(Dis)ability and (Dis)aster

Ilan Kelman and Laura M. Stough

Why This Book?

Traditional infrastructure, day-to-day life, and emergency procedures are designed for people without disabilities. It is assumed that human bodies have four functioning limbs; five functioning senses; and the cognitive ability to observe, interpret, and respond to the world in a normative fashion. However, an estimated 20 percent of the world's population experiences physical, sensory, cognitive, or mental health issues (World Health Organization, 2011) not typically considered or accommodated in our societal and built environment. Society assumes normed functioning and often disregards those who walk, talk, or think atypically. Unfortunately, such marginalization often leads to calamitous experiences during disasters—experiences that are rarely recorded.

This book presents firsthand narratives, written by individuals with disabilities from around the globe, about disasters and disaster risk reduction. These narratives range from surviving an earthquake in urban Costa Rica to surviving the "everyday disaster" of walking down a street in Ireland. Some of these authors acquired a disability as a result of disaster- as did a one writer who lost her leg in a nightclub fire in Brazil. Some recount how acquiring a disability increased their awareness of disaster preparedness and made them agents of change, as did a researcher in Kansas. Some of these individuals did not survive, such as in the case of a woman in a wheelchair who drowned while Hurricane Katrina's waters rose around her. A number of these narratives come from professionals within the field of emergency

management or international development, while others are disability advocates or researchers. From a tsunami in the Cook Islands to fire alarms in Norwegian hotels, these authors exchange disaster-related challenges, sometimes unusual and sometimes day-to-day, in their own voices.

A second purpose of this book is to provide thoughtful academic explorations of why and how hazards affect people with disabilities. Academics from two different continents and two different research traditions contribute perspectives on the wider sociological, environmental, and policy factors that place some individuals disproportionately at risk during disasters. Their chapters provide broad backdrops against which to situate the individual disability-authored narratives.

Brenda D. Phillips's chapter uses three frameworks to explore the intersection of disasters and disabilities. First, an overview of emergency management practices is reviewed across the disaster phases of preparedness, response, recovery, and mitigation, which have historically placed people with disabilities at risk. Phillips employs an ecosystem framework, allowing for analysis at different societal levels, to explain how people with disabilities are placed differentially at risk. Finally, Phillips uses a functional-needs framework, in which support needs, rather than disability diagnoses, are used for planning and providing disaster response.

In a second academic chapter, David Alexander argues that a fundamental reorientation is necessary for including people with disabilities in emergency plans, as civil protection systems have been historically designed for the mainstream population. He discusses how disasters, wars, and the hazards that accompany them, including bombs and landmines, also lead to disability. Finally, Alexander discusses how legal instruments and rights, most notably the international Sphere standards developed in 2011, have affected emergency procedures that provide support to people with disabilities. He cautions that an "adoption gap" separates what researchers and policy-makers have

concluded is best practice from the actual adoption of these practices by international organizations.

Finally, we, the editors, explore a third perspective, one that presents a critical examination of the intersection of disability and disaster. A common assumption is that the occurrence of disability and the occurrence of a disaster are both negative, in that they both are undesirable and deleteriously affect human life. Indeed, as part of their semantic construction, the term *disability* and the term *disaster* share the prefix *dis-*, connoting negation or lack; apart, asunder, or away; or having "a privative, negative, or reversing force" (Dictionary.com, 2014). At this level of analysis, the word (dis)ability can be perceived as inherently offensive, as it indicates a *lack of* or *absence of* ability. An analysis of the word (dis)aster similarly reveals that it comes from the pejorative root *dis-* joined with the Latin root *astrum*, together meaning *bad star* — connoting bad luck or the result of a misalignment of the astral heavens.

Many, including us and the authors in this book, have come to question these conceptions, both separately and together. Is it truly the case that disability means a limitation of ability? Is it truly the case that hazards must cause disasters? The chapters in this book seem to tell a counter-narrative; while disasters can and do negatively affect people with disabilities, people do not passively wait for a disaster to happen and then passively wait to be helped afterwards. Instead, people with disabilities respond actively to these "bad stars." Further, these authors, both in their individual narratives and in their scholarly reflections, suggest that disasters are not random, unexpected events (see also Hewitt, 1983; Lewis, 1999; Wisner et al., 2004). Disasters are actively designed by societies that fail to include the needs of all people. We further explore this counter-narrative by examining the separate constructions of (dis)ability and (dis)aster, and then these constructs at their intersection.

(Dis)ability: A Social Construction

For decades, the conceptualization of disability has been an ongoing and central discussion among disability scholars (e.g., Oliver, 1986; Shakespeare, 1998; Smart, 2009). Most recently, the social approach to disability has held sway. In this view, disability is seen as resulting from the interplay between external social factors and individual abilities and characteristics. This conceptualization departs from the biomedical stance in which disability is conceived of as an impairment or infirmity solely located within the individual. The biomedical conceptualization is clearly evidenced when an individual is diagnosed and assigned a disability label. For instance, a woman who receives a head injury and subsequently experiences memory loss might be given the label of "traumatic brain injury." Following this diagnosis, and based on that label, she is then prescribed certain medical, rehabilitative, and psychosocial treatments. In contrast, the social approach to disability focuses on the resources and services that an individual requires, and the ways in which the environment needs to be modified so that people can be as independent as possible in day-to-day living. In our example of the woman with a head injury, the social approach to disability would focus on the daily living supports that the woman needed, such as supported employment or transportation alternates, thereby allowing her to live as independently as she desired.

Some authors (e.g., Abberley, 1987; Devlin and Pothier, 2006; Oliver, 1986) scrutinize how individuals with disabilities have been politically and economically marginalized throughout history. These Critical Disability theorists challenge traditional paradigms, such as the biomedical model, on the basis of power relations, injustice, and inequality. Many disability activists and theorists hold that disability is completely a social construction, in that without these society-created barriers, differences in abilities would be equalized (e.g., Devlin and Pothier, 2006; Oliver, 1986, 1996). Others argue that conceptualizing disability as completely social in nature overlooks or minimizes the corporeal experiences and physical sensations of people with

disabilities (see Anastasiou and Kauffman, 2013; Hughes and Paterson, 2006).

To conceptualize how the social-environmental milieu affects people with disabilities, disability theorists employ constructs such as equity, inclusion, accessibility, stigma, segregation, or accommodation. For example, the construct of equity encompasses *equity of service*, in which people should be entitled to receive the same levels of service and *equity of access* , in which all people should be entitled to equal access to those services. Two examples illustrate these parallel concepts from the experiences of individuals with visual impairments. In July 2013, Canada's government mass distributed by mail a flyer advertising job creation for Canadians. The flyer contained words in braille, ostensibly so that people with visual impairments could also understand the content. However, the braille lettering was completely flat, without the raised dots that permit people's fingers to feel and hence read braille. In this case, the same flyer was sent to all, providing equity of service, but not all could read the information, thus preventing equity of access for people with visual impairments. A flip side occurs in US classes where children are learning to read braille. Teachers often translate reading materials from print to braille but, unless the teacher has a high level of braille expertise, these translated materials frequently contain spelling errors, grammatical mistakes, or are even unreadable. As a result, these students have equity of access to reading materials, but are not provided equity of service. In both of these examples, more thoughtful action would have prevented inequities.

Disasters, and the circumstances that surround them, similarly occasion difficulties in equity of access and equity of services. Individuals who are hearing impaired and who cannot understand announcements made over a loudspeaker in a shelter experience inequity of access. If poorly translated signed interpretation of those same announcements are provided, they do not receive the same information—an inequity of service results. Appropriate inclusion of people with disabilities in emergency response and recovery efforts

involves not only *what* is provided, but also *how* it is provided. It is not sufficient to provide food and shelter that only addresses the needs of the majority. Everyone who is affected by disaster should have the right to receive services that are accessible, inclusive, and equitable.

In addition, people with disabilities are not simply overlooked or ignored; often they are seen as a burden on society, a problem to be solved by others, or a special case to be "treated." Too often general measures are taken so that a box can ticked that "the disabled" are now "taken care of." In addition, little is known about how a specific hazard might differentially affect people with disabilities (Stough and Mayhorn, 2013), which results in emergency measures that are vague and unfocused. Many of these measures also tend to be visible and concrete, such as creating registries of people (which might or might not be used) or changing infrastructure to adapt to needs (without always considering that such needs also change and that infrastructure requires maintenance). Furthermore, people with disabilities are often considered a single homogenized group- "people with disabilities"- despite the incredible diversity represented within the group. Finally, rarely is it acknowledged that people with disabilities and their social networks can best explain what they require to be appropriately included in disaster risk reduction and response.

(Dis)aster: A Social Construction

I n the disaster research literature, the social vulnerability approach is increasingly used to conceptualize how disasters disproportionately and negatively affect different groups of people (e.g., Morrow, 1999; Hewitt, 1983, 1997; Lewis, 1999; Wisner et al., 2004). Wisner et al. (2004) suggest that disaster researchers need to move away from a focus on "vulnerable persons" and refocus on "vulnerable situations" within which some people are placed at increased risk more than others (see also Hewitt, 1983; Lewis, 1999). The social vulnerability approach posits that societal practices, including economic, political, and cultural factors, place people at risk. It is these practices that increase vulnerability and

create disasters, not hazards such as tornadoes and earthquakes. In this view, it is human society, rather than nature, that deems who is more likely to die or be injured by hazards, as well as who will have fewer resources to deal with these same hazards (Hewitt, 1997).

While hazards occur indiscriminately within space and time boundaries, the effects of disaster are *not* equal. Disasters particularly disadvantage poor people who live on unstable slopes and cannot afford to move; children who are dependent upon their parents for evacuation assistance; those who cannot understand the language in which warnings and announcements are made; caregivers (most frequently women) for elderly parents and children; and (most frequently) men expected to play rescuer roles and place themselves in danger. Edwards (2000) stated, "Disasters may not discriminate, but they do expose and underscore the inequalities that already exist in the communities they impact." In this view, vulnerabilities pre-exist in society as chronic, ongoing conditions (Lewis, 1999) and are only unmasked by hazard, thus making vulnerabilities visible as the disaster emerges. As an example, those living in substandard housing suffer more property damage and then have fewer resources for post-disaster repair (Van Willigen et al., 2002). Such differential impact also manifests during recovery. For instance, those without personal transportation (which also would have enabled self-evacuation before a storm) are differentially disadvantaged post-disaster when they cannot travel to obtain recovery services or resources. Social vulnerability theory thus explains how diverse groups differentially experience hazards.

Merging Voices on Disability and Disaster

The intersection of the two fields of disability and of disaster in this book stems from a collaboration between two editors, together with a collaboration among researchers and non-researchers, both with and without disabilities, some who are already authors and some who are first-time authors. As such, this book is not simply *about* people with disabilities, but written *by and with* people with disabilities.

As editors, we sought to go beyond "giving voice" to people with disabilities and invited them to "take voice" through authorship. Doing so meant that some of these chapters were spoken and transcribed, some translated, and some co-authored, but always under the direction and approval of individuals with disabilities. We believe such collaborations help mitigate criticisms of disability researchers who reinforce power differentials when they present disability as "personal tragedy" (Barnes and Mercer, 1997) despite the admonishment of "Nothing about us without us" by disability advocates (Charlton, 2000). Families of people with disabilities, too, negotiate disability and disaster, so we included their narratives, particularly when they could give voice to relatives with barriers to writing their own narratives.

A challenge in giving voice to diverse perspectives on disability from around the world was navigating the use of disability-related language and terminology. Even though we, the editors, come from two English-speaking countries, we found through the process of writing that our concepts of and nomenclature for "disability," "impairments," or "functional needs" differed. In our writing together, we chose to use "people-first language," as is the practice among disability advocates in the United States, and to use the word "disability" since it is the most universally word in usage and we write here for an international audience. Our use of the term "disability" is as a phenomenon resulting from the interaction between individual capacity and the environment, in keeping with social-environmental theoretical constructions of both disability and disaster.

Editing the narrative chapters heightened our semantic and conceptual challenges. Disability advocates who speak English may find some of the disability-related language used by some authors offensive. Some of these narratives lean toward a biomedical model in their portrayal of disability. In addition, our academic authors not only come from different continents, but also from different academic disciplines, including sociology, geography, and disability studies—each with their own epistemological perspectives and research terminology. In the end,

our preference was to use a light hand in editing disability-related language and discourse, for two reasons.

First, we recognize that authors with disabilities have the right to choose how they self-label and self-identify: Changing their language seemed too close to changing their voice: If people feel that they "suffer" and need "protection," then it is their right to express their narrative in that manner. Second, both our audience and our authors are international, and disability nomenclature and definitions used around the world, among the multiple disability and academic communities across the globe, defy standardization. As a result, some of our authors use constructs and language not universally acceptable simply because people with disabilities around the world describe their experiences in diverse ways. The accounts written here are, indeed, "Explorations and Exchanges" in how disability is viewed and voiced among and between many different disability discourse communities.

Despite these efforts, a potential drawback of this volume is that we, the editors, are not ourselves currently individuals with disabilities. Nevertheless, as with most readers of this book, we have friends and family members with disabilities and we drew from our lived experiences and exchanges with them to inform our research, editing, and writing. To further attempt to break down the non-disability/disability dichotomy, we note that our (and possibly your) own status as "able bodied" (i.e., "without disability") is temporal. We all are likely to acquire disabilities as we age, and similarly, we all are at risk for acquiring a disability due to disaster.

We also acknowledge that this volume, to an extent, perpetuates inequity of access and service, which simultaneously we, and our authors, criticize. Specifically, this book is available in only English and is not available in large print, audio book, braille, or other formats. We recognize the hypocrisy inherent in this situation and, despite these shortcomings and the barriers that they create, hope that our volume will inspire others to do better.

(Dis)ability and (Dis)aster

Who makes the choices that place some people's abilities "apart," "asunder," or "away," and why are those choices made? Who makes the choices that place some under an "unlucky star," while others escape disaster relatively unscathed? Connecting disability and disaster theory suggests some disturbing answers. The social constructs of disability and disaster reframe traditional perspectives on vulnerable populations and highlight society's role in establishing and perpetuating inequality. We as a society have not planned for the needs of diverse people and, by not doing so, we repeatedly create barriers, limit independence, and place people at risk. The intersection of disability and disaster thus reveals the structural aspects of society that cut across more than one phenomena, in this case people with diverse characteristics and people experiencing hazards. As Hemingway and Priestley (1996) note, "Just as disability is not the inevitable outcome of functional impairment, human 'disaster' is not the inevitable outcome of natural 'hazard'." (p. 58). We have constructed a world that is not inclusive of all abilities; thus creating disabilities. We have constructed a world that does not protect all from hazards; thus making some people experience disaster.

At the same time, while disaster vulnerability theory and the social model of disability provide powerful lenses through which to interpret the experiences of diverse populations, these perspectives also obscure an essential element: The experiences of individuals themselves. While external, environmental factors can lead to exclusion and risk, this social perspective somewhat conceals the individual perspective. We offer, therefore, the narratives in this book to bring individual voice into the social vulnerability perspective on disaster and disability hoping they provide a new perspective; one that allows us to discover, dissect, and reduce the distance between what happens and what ought to be when disaster and disability intersect.

Our perception of disability, as well as any other salient characteristic, can overshadow, label, and dictate our assessment of a person's disaster-related abilities. As Julia Gillard, Australia's first female

Prime Minister, reflected on her political vulnerability, "The reaction to being the first female PM [of Australia] does not explain everything about my prime ministership, nor does it explain nothing about my prime ministership." That is the same for people with disabilities. Disability does not explain everything about vulnerability to disaster. One author here, Christy Hardinger, similarly said about her disability "That's not who I am. Not at all." People need to be included in society on their own terms, without allowing definitions, barriers, or vulnerabilities to define them.

Evidence of people with disabilities who have defied barriers are common. Stephen Hawking, almost entirely paralyzed by a motor neuron disease, became a renowned theoretical physicist and best-selling author of popular science. Vincent Van Gogh painted the view from the room where he was hospitalized for his mental health, resulting in the masterpiece, *Starry Night*. Amy Purdy, with a double leg amputation due to bacterial meningitis, became a Snowboard Cross Paralympic bronze medalist, a television star, and ballroom dancer on Dancing with the Stars. However, these examples are often criticized by disability scholars and advocates for creating the expectation that all individuals with disabilities can simply overcome societal barriers (Smart, 2009). We affirm that the barriers described by the authors in this book are considerable, and that the disaster milieu increases these challenges.

The 2013 International Day for Disaster Reduction emphasized that disability is not inability. Society can and should do better to highlight ability, not disability, in dealing with disaster risk reduction and disaster response. Society creates disaster vulnerability, but can also choose to reduce it. One method of doing so is by ensuring that people with disabilities are included in disaster risk reduction and disaster response (for example, see World Health Organization, 2013). In addition, people with disabilities must be acknowledged as having the same rights to disaster-related services as do people without disabilities. It is up to all of us, both those with and those without disabilities, to include one and

all in disaster risk reduction and disaster response. Disability and disaster need not contribute to "a privative, negative, or reversing force" as per the definition of "dis." We hope that our volume contributes to such efforts.

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